



# DRAVET Syndrome UK

Hope for families with life-limiting epilepsy



*Join us today and contribute to making a lasting difference in the lives of those we support.*

**Head of Marketing & Communications  
Candidate Information Pack  
September 2023**

*DSUK has made a huge difference to people living with Dravet Syndrome. It has raised awareness of Dravet Syndrome, represented people affected by Dravet Syndrome, has been a source of support to which I can refer families, and has raised funds for, and funded, much research into the condition.*

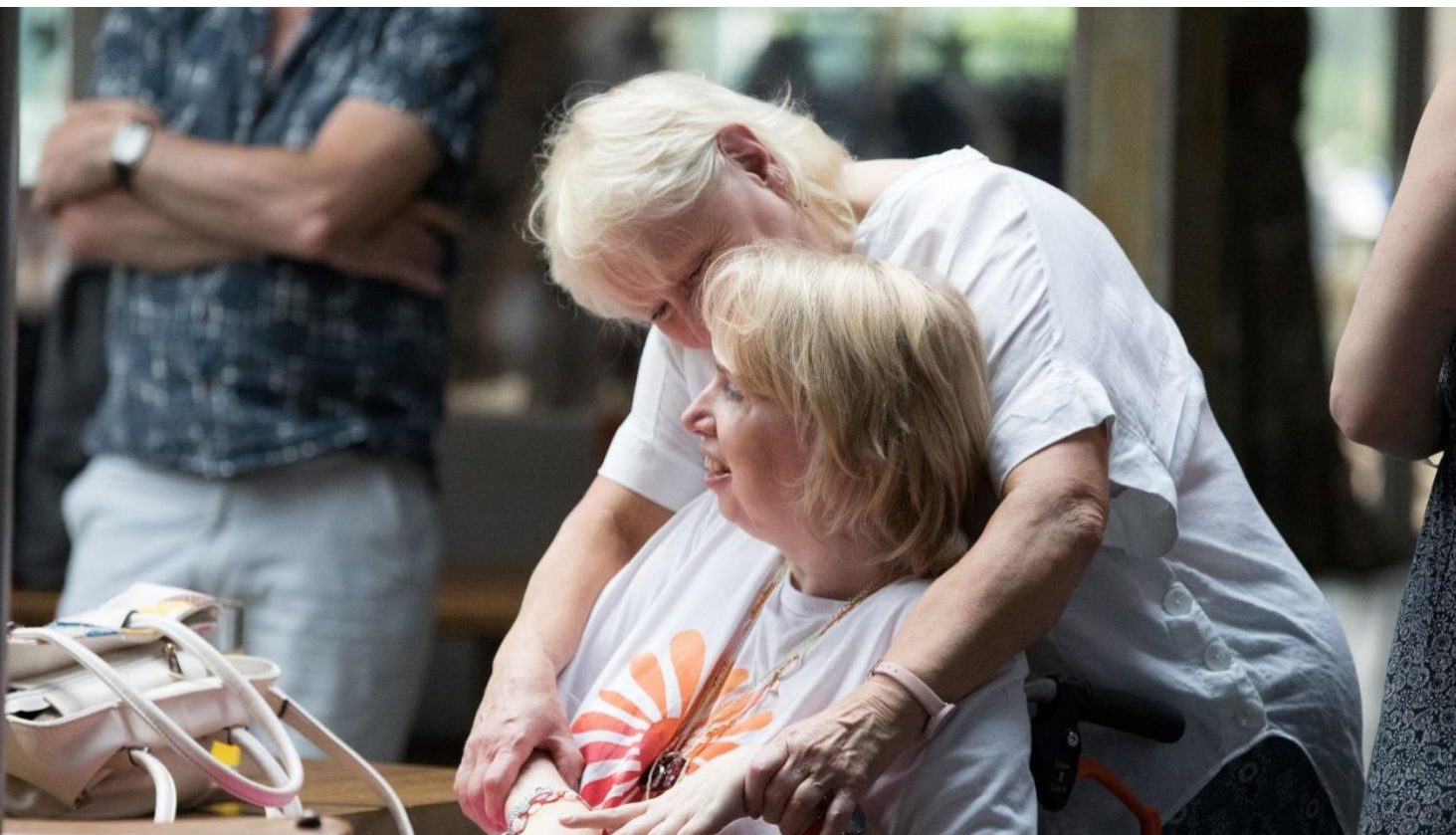
Professor Sanjay Sisodiya, UCL Institute of Neurology



## About us

Dravet Syndrome is a rare life-limiting neurological condition, occurring in around 1 in 15,000 live births. It's often described as a form of epilepsy; however, epilepsy is just one aspect of Dravet Syndrome. As well as severe, difficult-to-control seizures, children and adults with Dravet Syndrome have varying degrees of learning disability and a spectrum of associated conditions – known as comorbidities. These can include autism, ADHD, challenging behaviour and difficulties with speech, mobility, eating and sleep disorders. Dravet Syndrome is a devastating condition that has a huge impact on individuals, caregivers and their families.

Dravet Syndrome UK (DSUK) is a small, independent charity dedicated to improving the lives of those affected by Dravet Syndrome through support, education and research. The charity was founded in January 2009 by a small group of 30 families. Today, there are over 500 families registered with us and we have gained international respect and recognition for our work to bring hope to families affected by this catastrophic condition. We are also privileged to work with a world-class [Medical Advisory Board](#), whose guidance helps inform our activities. In 2021, we launched our [first five-year strategy](#) - a roadmap to guide our mission and enable us to reach more families, educate more professionals and fund more research.



## A message from the Chair

We're excited to commence recruitment for a Head of Marketing and Communications to join Dravet Syndrome UK. We are looking to fill this pivotal senior role, following the appointment of Claire Eldred (who previously held this position) as Director earlier this year.

Families are at the heart of everything we do at Dravet Syndrome UK. As a parent of a 15-year-old boy with Dravet Syndrome, I know first-hand the difference that the charity's support can make to the lives of families living with this devastating condition, and the importance of being able to connect with other families, apply for grants, access the latest information, know that clinicians are part of the conversation, and that vital research is being undertaken.

In recent years there have been exciting developments in the medical and scientific environment surrounding Dravet Syndrome. With advances in genetic research, there are new gene therapies on the horizon and other treatments in development. Dravet Syndrome UK is also committed to funding new research that puts family needs first.

In addition to the external environment, the charity is growing quickly, and our families face many urgent needs. We are currently mid-way through our 5-Year Strategy, and to enable us to achieve our strategic goals, we are looking to recruit a skilled and passionate professional, with the experience and drive to increase the impact of our work, by helping us reach new audiences and strengthening our reputation among stakeholders.

We're really looking forward to growing our team with this significant new appointment. Together I know we can make a real and lasting difference for every family living with Dravet Syndrome in the UK.

[Eastside People](#) are managing the recruitment process on our behalf and they will be delighted to discuss this opportunity with you.

We look forward to receiving your application.

**Galia Wilson, Chair of Trustees**

# Head of Marketing and Communications

<b>Salary</b>	£45,000 to £50,000 per annum pro rata
<b>Location</b>	Remote, with a requirement to travel to national meetings (approx. six times a year) and international conferences/events (approx. three times a year)
<b>Contract Type</b>	Permanent, open-ended
<b>Hours</b>	24 hours per week (0.6 FTE)
<b>Reports to</b>	Director
<b>Benefits</b>	24 days annual leave pro-rata plus 8 Bank Holidays per annum FTE. Pension in keeping with statutory requirements.

As part of **our commitment to safeguarding** the postholder is expected to undertake an enhanced DBS check.

## Job Purpose

Being part of the Senior Leadership Team, this role has the overall responsibility for the development and implementation of DSUK's marketing and communications strategy. The post holder will have a critical role in maintaining and developing DSUK's reputation, promoting the charity and its services, raising awareness and understanding of Dravet Syndrome, including among diverse and hard-to-reach audiences and engaging DSUK supporters.

As a smaller charity with big ambitions, DSUK utilises technology and partnership working to maximise its reach to people impacted by Dravet Syndrome. This role is both strategic and operational and will work closely with the Director and wider DSUK team. This role has a dotted-line responsibility for Marketing, Communications and Fundraising Manager.

## About the Team

Close teamwork is essential at DSUK. Our small team is home-based (no central office) but remains closely connected throughout the working day, utilising remote working technology. As part of the senior team, you will actively contribute to the strategic direction, planning and leadership of DSUK. You will show an aptitude for teamwork and collaboration and will work closely with the Director and the Marketing, Communications and Fundraising Manager. You will know about safeguarding and understand the importance of embedding an open, honest, and transparent culture.

## Key Responsibilities

### Strategic Planning

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- Overall responsibility for developing and implementing DSUK's marketing and communications strategy to promote the charity and its services, raise awareness and understanding of Dravet Syndrome and engage DSUK's supporters.
- Report to the Board of Trustees routinely and ad hoc as required on strategy, progress against targets and forward planning

### Digital Media

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- Provide strategic direction on DSUK's digital media work, including developing and maintaining an overarching Marketing and Communications strategy, aligned to DSUK's strategic objectives.
- Optimise the implementation of the Marketing and Communications strategy, providing oversight to and working with the Marketing, Communications and Fundraising Manager across all digital platforms (e.g. social media, website, e-newsletters, etc).
- Support the development of compelling case studies, utilising written materials, images and video footage as appropriate to convey critical messages and support diversity and inclusion.
- Commission and manage external suppliers as needed in the production of DSUK's digital content (e.g. photographers, video producers, designers and printers).

- Evaluate the success of activities to improve future engagement and report insights and recommendations to DSUK's Board of Trustees.

## Professional Engagement

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- Work with the Director to develop and implement Dravet Syndrome UK's strategic objectives of 'Supporting Professionals' and 'Leaders in the Field.'
- Maximise marketing and communication opportunities around DSUK's Research Fund (more information available [here](#)), including working in partnership with other patient advocacy groups.
- Lead content planning for professional-facing channels/activities, including the Professional section of the DSUK website, Professional e-newsletters, the DSUK Conference, and Professional Webinars, maximising opportunities to engage target audiences and raise awareness and improve understanding of Dravet Syndrome (target audiences include: including paediatricians, paediatric neurologists, adult neurologists, epilepsy nurses, and emergency service professionals. Other professionals include social care professionals, special needs educators, and professional carers).
- Identify and attend external events with target groups (e.g. BPNA Conference), approaching organisers early on with ideas to promote engagement on Dravet Syndrome.

## Information Materials

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- Lead on the production and update of DSUK's information materials (see, for example, our recently updated Family Guide), ensuring they are factually accurate, up-to-date, compelling to read, resonant with diverse audiences and brand compliant. Commission writers as appropriate.
- Work closely with families and professionals to capture their information needs and then use this to inform the development of new information materials.

## Teamwork

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- Lead and support the Marketing and Communications function within DSUK and be a source of expertise, knowledge, support and guidance for colleagues, instilling a culture of professionalism and inclusion
- Demonstrate excellent team management skills, with the ability to motivate and coach colleagues with the aim of working towards shared goals in a small team environment, undertaking line management as required.





# Person specification

## Experience, Skills and Knowledge

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### Essential

- Demonstrable experience of working in a small team, with the ability to motivate and coach colleagues to work towards shared goals.
- Demonstrable experience in developing and implementing marketing and communications strategies, as well as performing both operational and strategic duties in a similar role within the charity or healthcare or social-care sector
- Experience with one or more of the following groups: patients, patient advocacy groups, healthcare professionals, social care professionals and pharma.
- Ability to deal with people at all levels with empathy, tact and credibility.
- Excellent written and verbal communication skills, with an ability to distil large amounts of information and present it in engaging and innovative ways for a variety of audiences (including diverse and hard-to-reach audiences).
- Good understanding of brand, visual identity and corporate communication.
- Strong organisational and project management skills, with the ability to prioritise.
- Experience in utilising a CRM and/or CMS to maximise engagement potential and optimise online activity (including understanding of SEO).

### Desirable

- Good understanding of, and strong interest in, developments in UK health and social care
- An understanding of the issues affecting families living with a life-limiting condition
- Confidence in working with complex medical or scientific terminology
- Experience of working with vulnerable people and understanding of safeguarding best practice.
- Good understanding of Microsoft Office packages, Google suite and desktop publishing packages.

## Why should you join us?

Join our dynamic and growing charity, where you'll thrive in an exciting and engaging environment. As a highly regarded organisation with an excellent reputation, we are looking to expand our team to enable us to maximise marketing and communications opportunities across our target audiences. We are proud to be a family-oriented charity experiencing financial growth and fuelled by an ambitious plan for expansion. Our dedicated team is deeply connected to our core audience, and their motivation stems from witnessing our profound impact on people's lives. Working alongside inspiring families, you'll see first-hand the incredible love and dedication they have. Join us today and contribute to making a lasting difference in the lives of those we support.



## How to apply

[Eastside People](#) is supporting Dravet Syndrome UK in recruiting for this role. Please click [here](#) to apply by submitting your CV and a covering letter indicating why you are interested in applying for this role and how you meet the selection criteria.

If you would like a call to discuss the role in more detail, please email Renu Gundala, [renu@eastsidepeople.org](mailto:renu@eastsidepeople.org) to arrange a convenient time. Having a call of this kind will not influence the success or otherwise of your application.

We want you to have every opportunity to demonstrate your skills, ability and potential; please contact us if you require any assistance or adjustment so that we can help make the application process work for you.

The closing date for applications is **Monday, 25 September 2023**, with shortlisting interviews taking place the week after with Eastside People.

The first interview (virtual) with Dravet Syndrome UK will take place on **10 or 11 October 2023**. The final assessment includes an interview and a presentation, which will take place on **18 October 2023** in London.

## Our commitment to diversity

As part of our ambitions to improve equality and diversity, we welcome applications for this role from those who identify under any of the protected characteristics under the Equality Act 2010, which include race, age, disability, gender, religion or belief, and sexual orientation.



# Eastside People

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Eastside People is the trading name for Eastside Consulting Ltd. Company number: 4958922.